

European Reference Networks Conference

& ERNs Kick-off meeting

Vilnius, Lithuania 9-10 March 2017



Organised by the European Commission



MINISTRY OF HEALTH
OF THE REPUBLIC OF LITHUANIA

Hosted by the Ministry of Health of
Lithuania



Under the auspices of the Maltese
Presidency of the Council of the EU

9 March 2017

3rd European Reference Networks Conference
Vilnius, Lithuania

Venue: Lithuanian Exhibition and Congress Centre LITEXPO, Laisves pr. 5, 04215, Vilnius,

1. 08:00- 09:00h: **Registration and coffee**

2. 09:00 – 09:40h: **WELCOME AND OPENING SPEECHES**

- **Vytenis Andriukaitis**, Commissioner on Health & Food Safety
- **Françoise Grossetête**, Member of the European Parliament and former rapporteur of the Directive of Cross-border Healthcare (video message)
- **Aurelijus Veryga**, Minister of Health Lithuania
- **Christopher Fearne**, Minister of Health Malta

3. 09:40-12:15h: **MORNING ROUNDTABLES: EUROPEAN UNION DIMENSION OF THE ERNs**

09:40-09:50h: **Scene Setting and** introduction to the roundtables: **Xavier Prats Monné** (Director General, DG SANTE)

- **09:50-11.00h Roundtable 1: Operating European reference networks: organisation and management**

Chair: **Andrzej RYS** (Director, Health systems, medical products and innovation, DG SANTE)

Speakers:

- Coordinators view on network management and governance: **Alberto Pereira** (Coordinator ENDO-ERN).
- IT platform as core element of the work; eHealth and telemedicine: **Tapani Piha** (Head of Unit, Cross-border healthcare and e-Health, DG SANTE)
- Cross-linking European Reference Networks: **Maurizio Scarpa** (coordinator MetabERN)

- **11:05-12:15h Roundtable 2: EU Policies and Supporting Actions to the ERN**

Chair: **Despina Spanou** (Director, Digital Society, Trust and Cybersecurity, DG CNECT)

Speakers:

- Rare Diseases policies in the EU: **John F Ryan** (Director, Public health, country knowledge, crisis management, DG SANTE)
- RD-ACTION (mission and state of play of RD-ACTION, future challenges): **Victoria Hedley & Ana Rath** (RD Joint Action coordination)
- Rare Cancer Joint Action: **Paolo Casali** (JA coordinator and ERN EUROCAN representative).
- Registries platform: **Simona Martin** (Policy Officer, Health in Society, JRC)
- Research policies and ERNs: **Iiro Eerola** (Policy Officer, Innovative and Personalised Medicine, DG RTD)

4. 12:15-13:45h: **LUNCH, NETWORKING & POSTER SESSION**

5. **13:50-13:55h Scene setting for the afternoon roundtables: Justina Januseviciene** (Member of the ERN Board, Ministry of Health of Lithuania)

6. **14:00-15:10h: Roundtable 3: ERNs and national healthcare systems**

Chair: **Yann Le Cam** (Eurordis CEO)

Speakers

- Patient pathways and clinical governance: Patient flow Knowledge generation and clinical practice: **Jean-Yves Blay** (coordinator ERN EURACAN)
- Interrelationship between national systems and ERN: Member States view: **Nora Gamst** (ERN Board of MS, Norway's representative) and **Paul Boom** (ERN Board of MS, Netherland's representative)
- Coordination hubs and ERN: an example of best practice in Malta: **Miriam Dalmás** (ERN Board of MS, Maltese representative)

7. 15:10-15:40h **Coffee break & Poster session**

8. 15:40-16:50h: Roundtable 4: ERN: The way Forward

Chair: **Xavier Prats Monné** (Director General, DG SANTE)

Speakers:

- Health care provider perspective: **Arimantas Tamasauskas** (member of the ERN Neuro)
- Coordinator perspective: **Christopher Chapple** (Coordinator of the eUROGEN network proposal)
- Patient perspective: **Rebecca Tvedt** (patient representative in ERN BOND) & **Avril Daly** (patient representative in ERN-EYE)
- Member States perspective: **Till Voigtlander** (Chair of the ERN Board of Member States, Austria's representative)

9. 17:00-18:00h: **AWARD CEREMONY** (approved ERNs) (short introduction by Commissioner with the presence of MEP and Ministers)

- Certificates given by **Vytėnas Andriukaitis** Commissioner for Health & Food Safety

10. 18:00-19:00h **Cocktail and Poster walk hosted by the Lithuanian Ministry of Health to all participants**

10 March 09:00 to 14:00

Kick-off meeting of the 24 approved ERNs

Venue: Litexpo ;

Participants: 400 members of the 24 approved ERNs (*only for ERN members*)

1. **08:00-08:30:** Transfer from the Hotels and Welcome coffee
2. **08:30-09:00:** Walking coffee with Commissioner (ERNs Coordinators)
3. **09:00-12:00:** First session: separated meetings of the 24 ERNs
4. **11:00 to 12:00** parallel technical meeting: 23 ERNs Coordinators (grant holders) and CHAFAA
5. **12:00-13:00:** Lunch Break & Networking of all ERN members
6. **13:00-14:00:** Second session separated meetings of the 24 ERNs. Conclusions of the day
7. **14:00:** End of the meeting and transfer to Airport / Hotels